

Children's Specialized Hospital, 94 Stevens Rd., Toms River, NJ
Principal investigator: Yvette Janvier, Co-investigator: Jill Harris
Autism outreach/screening in underserved areas.
Grant No:10-400-SCH-H-0; grant duration: 2 years

Significance of grant for research in autism: Although no racial or ethnic differences have been found in the epidemiology or phenotype of autistic disorder, research suggests that both racial and income disparities exist in the early detection and treatment of autism. African -American and Latino children have been found to receive their first diagnosis at later ages than white children and poor children have been found to receive a diagnosis later than non-poor children. In addition, minority children have been found to be more likely than white children to be without health insurance coverage, to be without a usual source of care, and to report an inability to get needed medical care.

Primary healthcare providers are unlikely to adopt mental health screening or early intervention methods already developed in child psychology or psychiatry, even though such knowledge may be critical to child mental health promotion and early intervention efforts. This implies the need for targeted education among healthcare professionals regarding the diagnosis and treatment of autism and autism spectrum disorders among diverse populations, as well as among parents, caregivers, educators, and other community members who have regular contact with minority children to enable them to recognize characteristics in their children that might signal a developmental delay and a possible autism spectrum disorder. It also indicates the need for much greater accessibility to diagnostic services among poor and minority children.

This grant aims to increase identification of underserved children with ASD in six cities in New Jersey with large, low income, minority populations to enable access to appropriate services, thus resulting in early entry into appropriate early intervention services for a large number of underserved children who traditionally would not have been identified until after they entered elementary school. Focus includes determining utility of traditional screening tools and outreach materials with this population.

Other support: Grant personnel salaries are funded in part by Children's Specialized Hospital and in part by this grant.

Grant research activities to date:

- Autism outreach presentation materials were created; community screening processes and Autism Research evaluations were designed; database was created
- Autism outreach workshops for childcare providers and for parents have been given in 3 of the target cities; additional outreach scheduled
- Arrangements are underway to conduct community screening within Head start programs in the target cities

- Community screening was conducted at sites within Trenton and Bridgeton (169 children screened to date, resulting in six research autism full evaluations conducted to date; additional screening scheduled)
- Meetings were held with federally-funded health clinics in Bridgeton, New Brunswick and Newark to plan developmental screening clinics on site
- Meetings were held with community leaders, Statewide Parent Advocacy Network, and related agencies to raise awareness and facilitate grant-related activities
- Focus groups are scheduled in selected target cities
- Outreach materials currently in use are being reviewed by inner-city agencies and staff to help determine relevance and cultural sensitivity
- Introductory information packets were created and are being sent to all pediatricians, clinics, health centers, and pediatric practices in the target cities. These packets include offer to hold workshops at their offices or clinics
- Introduction letters have been sent to major child care centers in the target cities offering in-service Education
- Staff have attended training workshops to enhance understanding of disparity issues facing African-American, Latino, South Asian, and urban populations
- Staff have participated in community health fairs to raise awareness regarding autism and developmental delays

Preliminary findings: Based on community screening thus far, we are seeing a higher failure rate than expected based on existing research and note that there are potential barriers to use of traditional parent report measures in this population.

Publications: A poster describing preliminary data was submitted for presentation at IMFAR (International Meeting for Autism Research) annual meeting in May, 2011 but have not heard yet regarding acceptance.